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Sister Frances Dominica
Founder: Helen House

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LETTER FROM THE CHIEF EXECUTIVE

Dear Friends,

Where would any of us be without Helen House and its Founder, Sister Frances Dominica – our first Patron? Sister Frances, with huge vision, compassion and dedication, opened Helen House in Oxford in 1982, and this year we are celebrating with them 30 years of incredible service to children requiring palliative care. Helen House has been the inspiration for many programmes around the world, and we wish both to congratulate and thank all concerned for their leadership and example. May Helen House continue to be a beacon of hope for many years to come.

September is such a beautiful month – whether enjoying the glories of Spring in the Southern Hemisphere or Autumn/Fall in the Northern Hemisphere. Both seasons herald change and transition. Within the ICPCN we are also experiencing change, growth and transition. Our first change is the resignation of Lizzie Chambers as co-chair of the ICPCN. Lizzie was formerly Chief executive of ACT, which she led with vision and wisdom, and since the merging of ACT and Children's Hospice UK, working as Deputy Chief Executive of Together for Short Lives. We are however delighted that she remains on the Board of the ICPCN as chair of the new Information and Networking Committee, set up to support Sue Boucher as she leads our new and exciting venture, eHospice. Thank you Lizzie for all you have meant to the ICPCN from the beginning, and for your inspiring leadership.

Prof Mary Ann Muckaden, Head of the Palliative Care Department at TATA Memorial Cancer Hospital in Mumbai, will be our new Co-chair from

the 1 October, working alongside Barbara Gelb. We are delighted to welcome two new Trustees onto the board. Dr Zipporah (Zippy) Ali the Executive Director of the Kenyan Hospice and Palliative Care Association, and Stephen Connor (PhD) a Psychologist and International Palliative Care Consultant, representing the USA. There will be more detailed profiles of Prof Muckaden, Dr Ali and Dr Connor in the next Newsletter.

We are also delighted that the Duchess of Cambridge has chosen to draw the world's attention to hospice and palliative care both for children and adults by giving her maiden speech at home at The Treehouse Children's Hospice in Ipswich and her first speech abroad at Hospis Malaysia. Her endorsement for partnerships between hospices is also heartening and something that the ICPCN wholeheartedly supports.

The excellent Cardiff Paediatric Palliative Care Conference directed by Dr Richard Hain, focused on issues of spirituality. When speaking in different parts of the world, I have found that questions on spirituality and self-care are more common than questions on clinical issues but many people are still uncomfortable with the topic. We plan to set up a Reference Group to advise on this important element of palliative care for children. If you feel you would like to be part of this group, please let me know. Spiritual care is so often just being a caring and compassionate presence for the child and family.

May we all bring the gift of presence into our interactions with colleagues, children and families. With my very best wishes,

Joan

Countdown to the launch of ehospice - 2 October 2012

Launching in October, ehospice is a free website and app that will bring you real time international news and intelligence on hospice, palliative and end of life care – delivered by regional and national hospice and palliative care organisations worldwide.

At the touch of a button, you will find the latest news, commentary and analysis from across the world, bringing together the expertise and experience of the global hospice and palliative care community.

ehospice Palliative care news, views and inspiration from around the world

Available across web, mobile and tablet, ehospice will offer you a dynamic learning experience, including a directory of hospice and palliative care worldwide accessed via an interactive globe. To find out more about ehospice ahead of the launch on 2 October, sign up for regular email updates go to:

www.ehospice.com



INTERNATIONAL EVENTS CALENDAR: SEPTEMBER - DECEMBER 2012

More information and contact details for all these conferences, courses and events can be found on our website. Go to www.icpcn.org.uk

September

17	Launch of the South African Palliative Care Network	CTICC, Cape Town, South Africa	www.bigshoes.org.za
18 - 20	HPCA International Conference	CTICC, Cape Town, South Africa	www.hpca.co.za

October

04 - 06	Lebens Spannen - Fachtagung Palliative Care	Freiburg, Germany	www.lebensspannen.de/tagung/
05 - 08	International Society of Paediatric oncology 44th Congress 2012	Barbican Centre, London, UK	www.siop2012.org/
09 - 10	A Design for Life - UK CPC Practitioners' Conference 2012	The Paragon Hotel, Birmingham, UK	www.act.org.uk/
10	An overview of Teenage Grief	Derian House, Lancashire, UK	patricia.clarkson@derianhouse.co.uk
23	Training with the Palliative Care Toolkit - improving care in developing countries.	Hospice House, London, UK	www.helphospices.org.uk/
25	Supporting Parents through Pregnancy Loss and the Death of a Baby	Saunderton, Bucks, UK	www.childbereavement.org.uk/
30 - 2/11	2012 OVC Conference	Midrand, South Africa	www.ovc-conference.co.za

November

3 - 7	NHPCO's 13th Clinical Team Conference and Pediatric Intensive	Florida, USA	www.nhpco.confex.com/nhpco/CTC13/cfp.cgi
7 - 13	Program in Palliative Care Education & Practice	Harvard Medical School USA	www.hms.harvard.edu/pallcare/
8 - 11	Buddhist Contemplative Care Symposium	The Garrison Institute, NY, USA	www.zencare.org/symposium2012
12	Understanding Loss, Grief and Bereavement	Saunderton, Bucks, UK	patricia.clarkson@derianhouse.co.uk
14 - 17	8th International Conference on Pain Control and Regional Anaesthesia	Kochi India	www.icpra2012.com/index.php
26	Supporting Parents through Pregnancy Loss and the Death of a Baby	Manchester, UK	www.childbereavement.org/
27	Young people facing bereavement	St Christopher's Hospice, London, UK	www.stchristophers.org.uk/
28 - 1/12	6th Asian Congress of Pediatric Infectious Diseases	Sri Lanka	www.acpid2012.org/
28 - 30	1st European Congress on Paediatric Palliative Care	Rome, Italy	www.maruzza.org/congress/

December

2 - 5	3rd Int Conf on Pediatric Chronic Diseases, Disability and Human Dev	Jerusalem, Israel	www.isas.co.il/chhd/
5 - 7	Intensive Course on 'Nursing Ethics'	Leuven, Belgium	www.med.kuleuven.be

SACPCN Launch Meeting 17 September 2012 - CTICC in Cape Town



What is the SACPCN

The South African Children's Palliative Care Network, (SACPCN) has arisen out of the need to provide a forum for healthcare and other professionals as well as parents/caregivers to give input and support for an integrated approach to improve palliative care for children across South Africa.

What is the SACPCN launch meeting all about?

The launch meeting will provide an opportunity to bring leading experts in the field of PPC to a plenary session where they will share their knowledge and experiences with delegates. Speakers include:

Dr Khaliah Johnson

Visiting fellow from Children's Hospital of Philadelphia (CHOP)

Joan Marston

Chief Executive, International Children's Palliative Care Network (ICPCN)

Dr Michelle Meiring

Clinical Director Bigshoes Foundation and Paediatric Palliative Care Lecturer, University of Cape Town

The launch meeting will provide delegates with an opportunity to give input into and identify key areas of need for both the health care professional stream and the caregiver and family streams, as well as to elect representatives to guide the institutionalization of the SACPCN. The meeting will also provide an opportunity for stakeholders to network with each other and for organisations to showcase their work.

Who should come?

The launch meeting is aimed at child health professionals such as nurses, doctors, paediatricians, social workers, allied health practitioners, spiritual leaders as well as caregivers including parents, grandparents, NGO staff and home-based care workers. The meeting will be accredited for Continuing Professional Development Points for South African participants.

Book your place

Please complete the registration form at www.hpca.co.za

How much will it cost?

Health Care Professionals R750

Parents and caregivers R500

Find out more: www.bigshoes.org.za

Each year, more than 160,000 children are diagnosed with cancer worldwide and about 90 000 of these children succumb to the disease. Eighty percent of children with cancer live in developing nations and more than half of these children will die because they lack access to information, early detection, effective treatment and care.



The need for children's palliative care services in cancer care cannot be overstated. After accidents, cancer is the leading cause of death in children worldwide. Eighty percent of children with cancer live in developing nations and more than half of these children will die because they lack access to information, early detection, and effective treatment and care. Cancer pain can be excruciating and children often lack the verbal skills needed to express their level of pain. Unlike palliative care specialists, many health



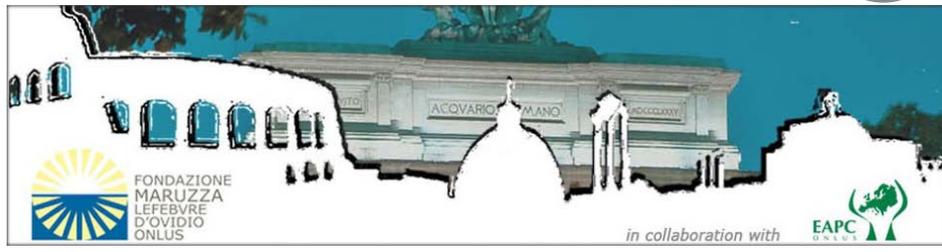
care professionals are not skilled or trained to evaluate a child's suffering and so it goes unrecognised, ignored and untreated.

Watch Dr Julia Ambler speak about palliative care for a child with cancer on ICPCN's new YouTube channel. Go to: <http://www.youtube.com/watch?v=v2Gaw8DqRw0&feature=plcp>

1st EUROPEAN CONGRESS ON PAEDIATRIC PALLIATIVE CARE

28 - 30 NOVEMBER 2012

1st EUROPEAN CONGRESS ON PAEDIATRIC PALLIATIVE CARE



The aim of the 1st European Congress on Paediatric Palliative Care is to provide an international platform for interdisciplinary knowledge sharing where experiences, current topics and new perspectives on key issues regarding palliative care for children and their families can be debated, compared and discussed by those working with critically ill children throughout Europe and beyond.

www.maruzza.org/congress/

Awards and scholarship opportunities



Applications are now being accepted for the AAHPM Developing Countries Scholarship. This scholarship is available to physicians who reside in developing countries to attend the AAHPM & HPNA Annual Assembly in New Orleans, March 13-16, 2013.

This scholarship programme will provide financial support (up to \$5,000) to physicians to learn the latest clinical information and research updates in hospice and palliative care from leading experts in the field.

To learn more and apply go to: <http://www.aahpm.org/learn/default/physicians-in-developing-countries-scholarship.html>

Please contact **Jennifer Bose** at jbose@aaahpm.org or 847.375.3688 with any questions.

Applications are now open for the 2013 STARS Impact Awards

The 2012 STARS Impact Awards recognises outstanding organisations working in children's health, education and protection in Africa, the Middle East, Asia and Pacific.

This year STARS has increased the number of Awards it intends to offer to 14. Of these, 6 Awards are made up of US\$100,000 of unrestricted funding and additional constancy support and the other 8 Awards will range in value from US\$15,000 to US\$60,000.

For information on previous Award recipients please visit the website.

www.starsfoundation.org.uk

World Hospice & Palliative Care Day - 13 October



The theme for this World Hospice & Palliative Care Day is **Living to the end: Palliative care for an ageing population**

In line with this theme the ICPCN has designed a series of posters showing that palliative care is applicable from the neonatal stage to young adulthood. ICPCN members are welcome to download these posters for printing. Should you wish the messages to be written in your home language, please make contact with our Information Officer on info@icpcn.co.za with the translations. Go to: www.icpcn.org.uk to download the posters.

Bayt Abdullah Children's Hospice in Kuwait seek a Medical Director and Head of Care

Bayt Abdullah Children's Hospice, the first children's hospice in the Middle East, is seeking a full time **Medical Director** of International Standing who will assume the overall responsibility for the medical component of the hospice programme.

They also have a position open for **Head of Care**. The applicant will be expected to run clinical day-to-day operations by providing professional and clinical leadership to the palliative care team, creating an environment and culture within the care team where quality and excellence are valued and clinical practice reflects the highest standards of care for children, young people and their families.

Applications are open until 2 November 2012. To find out more about these two positions go to www.bacch.org or send an enquiry to HR manager Sally Al Kot. E: sally.alkot@bacch.org Ph: +965 222 76 929



Hear My Voice:

Resources for Advance Care Planning for Children with Serious Illness

Meaghan Johnston, PhD(C)¹, RSW, Sharron Spicer, BSc, MD, FRCPC^{2,3}, Janet McFarlane, MSW, RSW³

(1) Mount Royal University, (2) University of Calgary, (3) Alberta Health Services

'Hear my Voice' is a tool for children and youth with serious health conditions and their families. It is a resource that can be used independently by families or in a facilitated manner with health professionals to promote decisions that are aligned with family values.

Support for decision making

The overall purpose of this project was to develop resources for families of children with life-threatening illnesses that would encourage an exploration of decision making from diagnosis, through the trajectory of the illness and at end of life.

While advance care planning is widely recognized as important, there are few resources available to families or health professionals to guide them through these important conversations.

The objectives of this project were:

- ▶ to develop family-centered resources
- ▶ to provide options for communication, both verbal and written
- ▶ to develop resources that encourage an inter-professional approach to advance care planning.

What is the tool?

Provided as a portable package of 52 cards available in a box or as a downloadable version, each card allows a choice of three questions that progress in complexity.

It includes a warm-up and wrap-up activity to provide structure.

It also includes safeguard cards to allow a player to 'pass' on a



question or to end the activity.

The cards or categories can be purposefully selected to address issues that are pertinent to the care of the child

Who can use this tool?

Initially designed for children and youth with serious health conditions and their families, this activity can also be used with individuals of all ages who are coping with chronic health conditions. The questions encompass a wide range of conditions and prompt consideration of all family members perspectives.

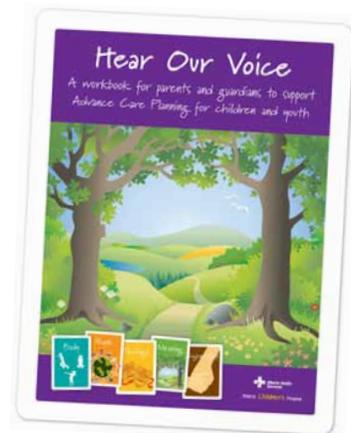
The questions are applicable to individuals coping with illness at any age and have been used effectively with adult populations.

Workbook

A complimentary workbook has been developed to support decision making in creating advance care plans. The workbook titled 'Hear



'Our Voice' provides families with an alternate or additional resource.



Acknowledgements

The creators of 'Hear my Voice' are thankful to Alberta Health Services, Alberta Children's Hospital and the Alberta Children's Hospital Foundation for making the development of this resource possible.

To order this resource or download a free copy go to:
<http://www.albertahealthservices.ca/4229.asp>

South Coast Hospice's Memory Box Workshops

*Written by Dominique Burton
Rural Home Care Programme Manager
South Coast Hospice
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HIV/AIDS is having a devastating effect on South African families and as a result children are paying a heavy price. Children are experiencing multiple losses as their circles of care break down under the strain of this pandemic. Their psychosocial well-being is therefore being compromised and since this is essential for their survival, there seems to be an urgent need for interventions that will allow children to experience the care, support and protection normally provided in a stable and loving home. It is through holistic interventions, that especially vulnerable children can be identified and assisted.

Resilience

Since resilience is the ability to cope despite adversity, psychosocial interventions need to ensure that they enhance resilience in the children participating in these programmes. This is achieved by building the protective processes found in the children themselves as well as in their families and communities so as to enable them to cope better in the face of adversities. One way to build resilience in especially vulnerable children is by these children participating in a Memory Box workshop.

Metaphor

The term **Memory Box** should be understood as a metaphor: it is a method that encourages children whose parents have died or who are very ill and will most likely die soon to preserve their memory of them in a way that will allow them to develop despite adversity. The term also

refers to an object: a wooden, metal or cardboard box or container that holds personal items such as photos, identity documents, objects belonging to deceased family members etc.



Children participating in a Memory Box workshop at South Coast Hospice

History

The essence of memory work rests on the hypothesis that it is good for the child to know his/her family history, however painful this might be, on condition that this history is recounted in a warm, non-judgmental setting. If the children know the history of their parents, they are better able to overcome the suffering caused by their illness or death. They access this knowledge through memory – their own and of those close to them, and for the grieving process to unfold in a meaningful way the children's perceptions and feelings need to be validated by supporting adults i.e. the memory facilitators. Further, these children will be able to provide emotional support to siblings, peers and younger children, and will in all likelihood become involved in further activities that encourage increasing awareness of self-development and realizing their full potential.

Resilience

The primary objective of a memory box workshop is to provide HIV-infected and affected children with life skills that will enhance their resilience. Special emphasis is placed on memory work, with

modules dealing with family stories and family trees. Under the supervision of memory facilitators, the children decorate their sturdy and specially-crafted memory boxes. The stories of their deceased parents, photographs, important life documents, as well as various precious objects and tangible treasures pertaining to their history are placed in their boxes.

Since 2008, South Coast Hospice has run 12 Memory Box Workshops for 265 especially vulnerable children. These workshops are facilitated by a Counselling Psychologist, 1 Social Worker, 2 Social Auxiliary Workers and 6 Children's Team Caregivers and run for five days during the school holidays.

Acknowledgements

Running the Memory Box Workshops has taught South Coast Hospice the importance of a communal response to providing for the needs of these very vulnerable children. The generosity of funding and of spirit is what has contributed to this successful programme. We acknowledge Sinomlando, our donors as well as our carpenter, caterers, concerned educators, staff and members of the public for all they have contributed.

Our experience with the Children's Palliative Care Team at Hospital Posadas in Buenos Aires, Argentina

Lais Fernanda Barroso Cremonesi and Renata Fernandes de Carvalho Moreno are two paediatric nurses from the Institute for Pediatric Oncologia (IOP-GRAACC-Unifesp) in Sao Paulo, Brazil who participated in an internship at Hospital Posadas in Buenos Aires, Argentina. They report on what they learnt and some of their experiences from the time they spent with the Children's Palliative Care Team under the guidance of Dr Rut Kiman.



The paediatric palliative care team based at Hospital Posadas in Buenos Aires hosted two paediatric oncology nurses from the Pediatric Oncology Institute in Sao Paulo, Brazil. Lais and Renata are 2nd from the left (top and bottom) and Dr Kiman is on the right.

During the internship, we had the opportunity to follow the Interdisciplinary Children's Palliative Care team in Hospital Posadas, Buenos Aires, Argentina, consisting of two physicians, a nurse, a psychologist, a sociologist, an occupational therapist, and other professionals who perform temporary stages in the service as 3rd year residents and a social worker. The team works with inpatients and outpatients, referred either by resident pediatric physicians, by pediatric consultants in charge of pediatric inpatient ward or by pediatric sub specialists.

The experience of doing this internship was extremely valuable and enriching, since the team is already well-structured and is widely recognized in the hospital. We saw the team working with patients with little chance of survival and with patients not only in the final stages of life. This is considerably different from the reality of our service. It proved to be extremely constructive because it made us think about the care we provide to our patients and how we can accomplish a great deal more.

Pain management

We found that the pain management is similar to what we do. During

the discussions we have had the opportunity to exchange experiences and gain new knowledge about the medications used, their mechanisms of action and the side-effects they cause.

We were asked to prepare a presentation on opioid-induced constipation, which was also extremely positive for our growth. We learned some scales used by the team to assess the level of sedation and that abstinence from opioids can be very useful in our practice.

Theory and practice

We had the opportunity to spend two days in the Hematology-Oncology Unit. We learned the routines of nursing work, the protocols used, and about the preparation of chemotherapy. We exchanged experiences on the reality we live in our service and we noticed the difference and difficulties of a pediatric oncology sector located within a general hospital.

Throughout the internship we had good theoretical support, either in discussions or through interdisciplinary classes taught during the week. This was critical to our advancement because we were

able to constantly relate theory to practical experience.

It was interesting to note the concern the team had for the emotional aspects of patients, relatives and health professionals involved in the care. They were aware of and concerned about the details that are not routinely observed, demonstrating the holistic nature of the treatment by the CPC team. This is very different to the biomedical approach to care.

Everything we experienced was an example of how people with determination, desire, knowledge and love for what they do manage to break down barriers and change cultural paradigms within a large hospital, overcoming the limitations and building a quality service.

In short, it was a very constructive experience for our personal and professional growth.

Activities performed included:

- ▶ Monitoring and participation in discussions of the cases seen by the team
- ▶ Observation of patient and family care
- ▶ Participation in discussions of cases of Paediatrics and classes taught by staff
- ▶ Presentation of a lecture on opioid-induced constipation
- ▶ Opportunity to meet the service of Pediatric Oncology and their work routines
- ▶ Implementation and application of a questionnaire on the use of opioids and Palliative Care for teams of Pediatric Oncology, and Cardiology ICU in order to identify the level of knowledge about opioids and activities performed by the palliative care team
- ▶ Exchange of experiences of the situations we experience in our service identifying the strengths and weaknesses of each service.



Lais Cremonesi and Renata Fernandes

QUEENSLAND KIDS - ONE STEP CLOSER TO THE OPENING OF HUMMINGBIRD HOUSE

Palliative care services and home and community care services inquiry

"You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully, but to live until you die" — Dame Cicely Saunders



submission by

Queensland Kids

ACN 149 413 356 Registered Charity CH2066
 www.queenslandkids.org info@queenslandkids.org

August 2012

Queensland Kids took another step forward in their mission to build a world class sustainable paediatric respite and hospice facility in Brisbane, Queensland.

Paul and Gabrielle Quilliam, cofounders of Queensland Kids were invited to present a submission to a recently held parliamentary inquiry into palliative care in Queensland. Queensland Kids were the only exclusive organisational paediatric palliative care submission. Included in the submission were parent's stories, including the stories of Kate and Amy from ICPCN's publication Touching Rainbows. QK were highly commended by the politicians on the quality of the submission and the stories.

Critical gap in services

Queensland Kids has identified a critical gap in services for out-of-home respite and end-of-life care for children and their families affected by a life-limiting condition. Queensland Kids' vision is to build Hummingbird House, Queensland's only out-of-home specialist paediatric palliative care, respite and hospice facility. Hummingbird House will be established to give families the added flexibility to access respite care and hospice care when home or hospital care can no longer meet their needs.

Paul and Gabrielle report on Queensland Kids Facebook page that two separate official responses from MP's on the inquiry committee were: "the need for this is a 'no-brainer'"....and "we commend you on your submission and thank you for providing the powerful stories".

They also thanked the families who supported their organisational submission saying "...those stories are not ours...they are YOURS and they have made a massive impact upon the future of paediatric palliative care in Queensland."

Queensland Kids have recently released their newest promotional clip which will be screened in cinemas. This can be seen on the front page of their website at: www.hummingbirdhouse.com.au

Why Hummingbird House?

Children's author Renee Bennet gives a wonderful analogy in her explanation of why the name 'Hummingbird House' was chosen for the hospice. In an extract from the submission she describes the similarities between children with life limiting illnesses and hummingbirds as follows:

Somewhere today in our vast world, is the smallest of birds, known as the Hummingbird. Though small in stature, it is an extraordinary creature. For this very reason, we have chosen to call this, Hummingbird House. Though small in stature, children living with a long term palliative disability are nothing less than extraordinary! Hummingbirds are continuously hours away from starving to death and are able to store just enough energy to survive overnight. They do not spend all day flying as the energy cost would be prohibitive. The majority of their activity consists of simply sitting or perching. The sad reality is that for these children, death could be just moments away and a lot of their energy is used in just trying to live.

While a hummingbird rapidly beats it's wings, it does this just to hover and remain suspended in the air. The journey of a child with a life-limiting condition can often seem suspended in time. Many never move forward on the journey of normal growth or development.



Hummingbirds are the only bird in the world that can fly backwards.

The journey of a child with a life-limiting condition is often one of backward motion...moving away from a full future. Hummingbirds don't use their feet to walk but for perching. Queensland Kids are often wheelchair bound and spend most of their life just sitting and waiting. Indeed, many Hummingbirds die in their first year of life during hatching and leaving the nest. If they do survive they can live as long as 10 years but the average lifespan is 3 - 5 years. Such a lifespan is similar in length when compared to a child with a life-limiting condition.

Hummingbirds are capable of covering astounding distances. Queensland Kids' and their families are capable of doing astounding things within their lifetime and making an astounding impact on those around them.

Paul and Gabrielle would be keen to partner with another Children's Hospice working in similar circumstances for the sharing of ideas, relevant policies and expertise. If you are interested in such a partnerships, please feel free to contact them by email at: paul@queenslandkids.org

The world's first children's hospice celebrates its 30th Anniversary

Milestones from 30 years of care

It has been 30 years since Helen House opened in Oxford, England. It was the first children's hospice in the world.

Throughout 2012 they plan to celebrating these 30 years of care, talking about one of the millstones in their journey each month through the use of videos and photos. They will also talk about their plans for the future.

The milestones they discuss include the following:

- ▶ The opening of Helen House in 1982
- ▶ The creation of their bereavement support team in 1985
- ▶ The support provided to siblings
- ▶ The opening of their first shop in Oxford in 2003
- ▶ The opening of Douglas House for teenagers and young adults IN 2004

They will also be celebrating their 30th anniversary with a travelling photographic exhibition, 'We are Thirty', which captures the images and stories of children, young adults and families behind both Helen House and Douglas House, from across the region. The exhibition starts its journey at The Central Library in Swindon on 17 July and takes in Banbury, Buckingham, Henley, Oxford, High Wycombe and Waddesdon Manor. The photos will also be shown at the charity's open day in Oxford, on Saturday, 15 September. To learn more about the celebrations in this special year go to: www.helenanddouglas.org.uk



HRH The Duchess of Cambridge makes her first official speech at one of East Anglia Children's Hospices (EACH) - The Treehouse



HRH The Duchess of Cambridge chose to give her very first speech as a royal at East Anglia's Children's Hospices newest hospice - The Treehouse. She is a patron of EACH.

While there she also spent time painting and making music with some of the children and planted a tree in the grounds. In her speech

she spoke of feeling hugely honoured to be here to see the wonderful centre and said that what was done at The Treehouse was inspirational and "a shining example of the support and care that is delivered not just here by in children's hospices at large up and down the country."

The Duchess admitted to having 'a pre-conceived idea of what to expect' on her very first visit to a children's hospice in Milton. Her surprise at finding a 'home from home' is summed up in her words: "Far from being a clinical depressing place for sick children. It was a home. Most importantly it was a family home. A happy place of stability support and care. It was a place of fun."

She described the children's hospice as a lifeline which enabled families to 'live as normally as possible during a very precious time.

The feelings you inspire. Feelings of love and of hope offer a chance to families to live a life they never thought possible.

What you have all achieved here is extraordinary.

I feel enormously proud to be part of East Anglia's Children's Hospice and to see the life-changing work that you do."

The Duchess's very first speech abroad on 13 September will also be at a hospice in Malaysia. To watch her maiden speech on YouTube go to: <http://www.youtube.com/watch?v=4cmYK805fUs>